

Welcome Back Campaign Evaluation: *How to encourage re-engagement with ART*



Authors: Melanie Bisnauth and Kate Rees

Introduction

When people living with HIV (PLHIV) stop their antiretroviral therapy (ART), they experience poor health outcomes- up to 30% of hospital HIV-related admissions are amongst people off treatment. They will also not be virally suppressed, which means an increased risk of transmission of HIV. The high number of people who interrupt treatment partially explains why HIV/AIDS related deaths are not declining in South Africa.

To improve morbidity and mortality and decrease transmission, we need to re-engage PLHIV who have been lost from care.

Why did we want to look at this?

The Welcome Back Campaign (WBC) was developed in collaboration with Médecins Sans Frontières (www.msf.org.za), and consisted of two parts:

1) training for health care workers on how to manage clients restarting ART and 2) mass media messaging about returning to care.

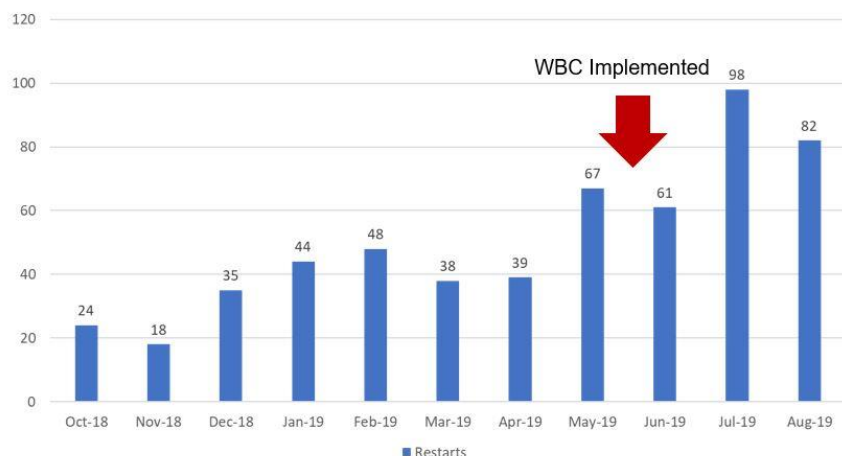
We wanted to understand whether the campaign led to an increased number of clients returning to care, whether the training led to changes in how clients were managed, and why clients interrupted treatment and decided to return to care.

What was our approach?

- The evaluation was conducted in 6 facilities of one sub-district of Johannesburg, Region E.
- We analysed routine TIER.Net data (including the number of people in care, and number of people restarting treatment).
- Implementation of the approaches covered in the Welcome Back training was assessed using qualitative interviews with health care workers.
- Understanding of clients restarting ART was investigated using surveys completed for clients returning to care.

What did we find out?

People restarting ART (Oct 2018 - Aug 2019)



Region E
had a 92% increase- almost double- in people returning to care- after WBC implementation. This was the highest increase amongst all the regions in Johannesburg.

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A total of 143 Welcome Back Client Forms were completed over an 8 week period (Jul-August) from 6 Region E facilities. The highest number of forms were received from Alex CHC and 4th Avenue Clinic.

WBC was implemented in May-June 2019, there was an increase in the # of restarts.

57% (82) of clients were between the ages of 25-39 years old, 27% (39) were 40-55 years old and 6% (9) were 20-24 years old.

 Women accounted for 62% (76) compared to men at 35% (43) and 2% transgender. 

Client characteristics for WBC

- 53% (56) clients were unemployed, 31% (33) employed and 14% (15) preferred not to answer.
- 91% (116) clients returned to the same facility vs. 9% (12) clients accessed a different facility.
- Of the 9%, 8 clients accessed care in the rural, and 3 clients in the peri-urban.
- 17% (22) of clients reported they knew their last CD4 count, 70% (93) stated they did not know their last CD4 count and, 14% (18) stated they don't know what CD4 is.

26% (35) of clients reported they were off of treatment for more than 1 year.

66% (36) of clients reported they were taking a fixed dose combination (one pill a day).



9% (10) of clients reported they miss their medication one or more times a week and an additional 9% of clients reported they miss their medication more than once a month.



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SO WHY ARE CLIENTS STOPPING ART?

16% of clients reported stopping ART due to moving, relocation or housing instability.



12% of clients were busy or couldn't get time off work.

12% of clients reported stopping ART for reasons related to the treatment itself: they felt tired of treatment; experienced ART side effects; felt too sick/worried to continue; started to feel better; didn't believe ART would work or was important; or didn't believe they should continue ART.



It is important to note that clients were asked these questions by counsellors, and they may not have wanted to say negative things about healthcare workers or facilities.

WHY DO CLIENTS RETURN?

29% (36) of clients reported it is easier to get to the clinic now.

21% (26) of clients reported they started to feel more sick.

16% (20) of clients **were** worried about not being on ART.



Why are clients returning to specific clinics?...

Clients select clinics based on the following reasons:

- 71% reported it was nearest to where s/he lives.
- 7% reported the clinic is nearest to their work.
- 5% reported their friend recommended the clinic.



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WHAT FACTORS KEEP CLIENTS IN REMAINING IN YOUR CARE?



24% (26) of clients responded that counselling would help keep them in care.

36% (40) of clients responded SMS reminders & 8% (9) check-in phone calls would help.



Only 12% (15) responded they did hear about WBC. However, 87% (13/15) clients that said 'Yes' they heard about WBC *also* stated 'the WBC influenced their return to care'. 75% (9) clients responded they received information from a clinic/hospital, compared to 17% (2) clients were exposed to WBC through radio.

A total of 36 healthcare workers were interviewed across the following 6 Region E facilities.

- Interviewees included nurses, counsellors and clinicians.



STAFF FAMILIARITY AND RESPONSIBILITY FOR WBC

- 97% (35/36) of staff responded they are familiar with the Welcome Back Campaign.

CLINICIAN AVAILABILITY/CLO NAVIGATOR

- 75% (27) of staff responded that there is a single clinician at the facility who sees all clients who come back to the clinic after a treatment interruption.
- 78% (28) of staff responded that there is a specific person such as a CLO designated to help clients navigate the facility and processes when returning to care.

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HEALTHCARE WORKER RESPONSES ON THE PURPOSE, AIMS AND OBJECTIVES OF THE WELCOME BACK CAMPAIGN

"When everyone is on meds and VLS it lowers new infections"

"To ensure all HIV clients are easily accessing treatment without blame, giving a second chance, allowing them to come back to facility without judgement"

"To educate and have patients understand the importance of taking RX, reducing LTFU"

"To reinitiate patients back to treatment and prevent opportunistic diseases"

"To reduce number of people who are positive and not taking meds, making sure they know their status and not feel intimidated"

"To help patients who come from far and need medication but don't have referral letters"

"To make our clients see how we really care about their health and important that new clients that disengaged to the treatment feel welcomed when they return to care"

"To bring people in to care that are not taking treatment and keep their health up to date"

"Prevent people from getting sick from HIV leading to AIDS, focusing on the 2nd 90, everyone should be on ART and VLS, eliminating the spread of HIV"

"To reduce the number of default patients without criticizing them"

"To manage clients and understand their stories, not make them guilty and explain processes"

ANOVA
HEALTH INSTITUTE

What happens at the facility when someone that returns after treatment interruption?

- Most healthcare workers provided positive answers as to how clients returning to care are managed at their health facility.
- However, 25% responded across 3/6 facilities that clients are sent to the back of the queue and staff insist on transfer letters.
- 94% (33) of staff responded they educate and offer differentiated care, 83% (29) welcome, and 77% (27) encourage those that return.

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Can you give me an example of the wrong things to do when people return to care?

- 74% (26) staff responded that sending an individual to the back of a queue or criticise/judge/punish.
- 66% (23) responded insisting on transfer letters are wrong things to do when people return to care.
- 25/36 (69%) staff responded stating they have seen or heard other staff members acting this way...



28% of staff insist on transfer letters, 7% lecture clients and 3% judge/refuse clients if previous treatment can't be proven, refusing ART.



Staff responses of what they have seen others do included the following examples:

"Yes, defaulting patients from ART treatment are refused treatment and are told to go back to their clinic where they started their treatment."

"Staff members shout at clients for refusing treatment and make them wait longer to be helped."

"Before this campaign, patients would be treated later after everyone else. The patient is sent to the back of the queue or they are rebooked for another date."

79% (23) staff responded they welcome, 62% (18) responded they create a treatment management plan followed by encouragement and education 59% (17).

How do you think we should treat people who return to care? Why?

"Welcome them and the express importance of counselling so that we avoid interrupting treatment again. Refer if necessary to a social worker- with no judgement." [R119]

"They deserve to be treated with dignity, respect and integrity, a good warm welcome back." [R123]

"They should be treated fairly without discrimination so they can be free to express their problems and difficulties." [R140]

"The welcome back campaign should be ongoing as this makes it easy for patients to communicate freely without having fear of being treated badly." [R94]

"Allow them to tell us their challenges with taking treatment and how can we change that to overcome these challenges." [R97]

"It is braveness on its own to have insight and come for their medication all over again. You may not know what caused them to stop." [R121]

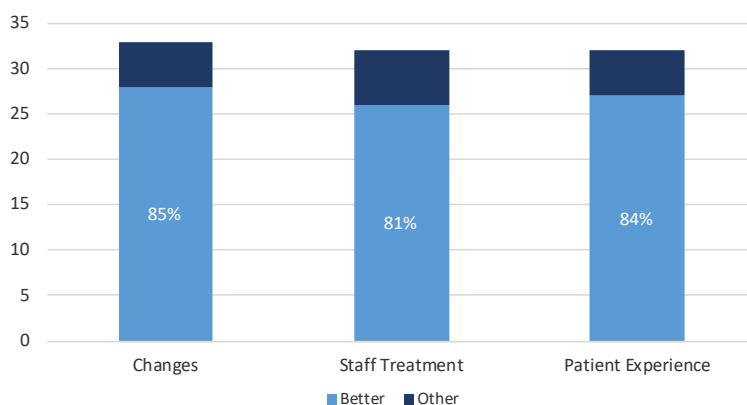
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Following the Welcome Back Campaign

- 85% (28) staff believed patient and staff relationships improved.
- 81% (26) believe staff treatment of patients improved.
- 84% (27) staff believe patient experiences improved.



TAKE-HOME MESSAGES

1

The number of people returning to care increased after the Welcome Back Campaign, however 88% of those clients had not heard any messaging.

2

Training may have sensitised/capacitated healthcare workers to probe more deeply into prior ART experience. Asking counselors to complete the forms for people returning to care may have also increased awareness.

3

The majority of clients restarting ART were doing so at the same facility. It is not known whether this finding would be different in other parts of Johannesburg, or whether clients were unwilling to tell counselors that they had been in care elsewhere before.

4

The most commonly reported reasons for stopping treatment were moving, relocation or housing instability.

5

Approximately 30% of clients said they restarted treatment when it became easier to get to the clinic again.

6

Close to 40% said they restarted because they felt ill or were worried about *not being on ART*.

7

The three most commonly requested support interventions were SMS reminders, counselling and check-in phone calls.

8

Most healthcare workers answered questions about how they treat people restarting treatment positively. However, 25% said such clients are sent to the back of the queue at their facility, and many reported seeing clients treated badly by other HCWs.

9

The majority felt that people restarting ART were treated better since the onset of the campaign.

SO WHAT?

The Welcome Back Campaign has supported healthcare workers to improve their approach to clients restarting ART. However, negative attitudes and practices remain. Clients will continue to face challenges in their lives that make it difficult to stay in care. We need to ensure health services are flexible enough, and healthcare workers understanding enough to minimise treatment interruptions when this happens. We need to focus on ways to improve accessibility of services when life gets in the way.